PARENTS WITH INTELLECTUAL DISABILITIES
Past, Present and Futures

Edited by

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'Parents with Intellectual Disabilities: Past, Present and Futures is essential reading for anyone interested in the lives of parents with intellectual disabilities, and it is recommended reading for everyone in the broader field of developmental disabilities. It provides a synthesis of current research and practice, along with a clear picture of the challenges ahead. Its contents are both comprehensive and compassionate. The international authorship provides an important global perspective.'

Dr Dick Sobsey, University of Alberta, Canada

'The birth of a new child tends to be a happy event, but if parents are intellectually disabled, it is likely to be associated with “danger” and a case for child protection agencies. The point of departure of this book, however, is the 2006 UN Convention on the Rights of Persons with Disabilities, Article 23, on the elimination of discrimination related to marriage and family. The book discusses the experiences of parents with intellectual disabilities and their children, and also supports such parental training and the role of extended families. It is a very welcome contribution to a topic that tends to be negatively oversimplified.'

Jan Tassebro, Ph.D., Norwegian University of Science and Technology
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We dedicate this book with great gratitude to our friends, mentors and colleagues Tim and Wendy Booth
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David McConnell, Professor in the Department of Occupational Therapy, Faculty of Rehabilitation Medicine, University of Alberta, has been conducting research in the field of parents and parenting with intellectual disabilities for over 15 years. His recent work has focused on child protection practice and child welfare court proceedings, and building systems capacity to support parents with intellectual disabilities and their children. Formerly Executive Director of
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Hanna Björg Sigurjónsdóttir is an Assistant Professor at the University of Iceland where she teaches about research methods and disability and does research with people with disabilities. She has worked with people with intellectual disabilities for many years, as an advocate, researcher, and an assistant in a parent group. Her doctoral thesis was centered on family support services and parents with learning disabilities. Together with Rannveig Traustadóttir she has published two books in Icelandic, *Contested Families: Parents with Intellectual*
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*Disabilities and Their Children* (University of Iceland Press, 1998) and *Invisible Families: Mothers with Intellectual Disabilities and Their Children* (University of Iceland Press, 2001).

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**Steven J. Taylor**, PhD, is Centennial Professor of Disability Studies and Director of the Center on Human Policy at Syracuse University. He has published widely on disability policy, the sociology of disability, and qualitative research methods. His 10 books include *Introduction to Qualitative Research Methods* (3rd edition), *The Social Meaning of Mental Retardation*, and *Acts of Conscience: World War II, Mental Institutions, and Religious Objectors*. He also serves as the Editor of *Intellectual and Developmental Disabilities*. He has been the recipient of the Research Award from the American Association on Mental Retardation (1997), the Syracuse University Chancellor’s Citation for Exceptional Academic Achievement (2003), and the first annual Senior Scholar Award from the Society for Disability Studies (2008).

**Rannveig Traustadóttir** is Professor and Director of the Centre for Disability Studies in the School of Social Sciences, University of Iceland. Much of her research in disability studies has examined the intersection of disability and gender, as well as other categories of inequality, such as social class, race/ethnicity, age and sexuality, and how these create multiple layers of discrimination and social exclusion in disabled people’s lives. She has been one of the leaders in developing disability studies as a scholarly field in the Nordic countries and is the former president of the Nordic Network on Disability Research (NNDR).

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Foreword

Should adults with intellectual disabilities be permitted to be parents? In most countries, the answer to this question was clear until relatively recent years: No, they should not. The dramatic growth in the populations of public institutions in the late 18th and early 19th centuries in the United States of America and elsewhere was fueled by the fear that the “feebleminded” would pollute society with their defective genes if allowed to reproduce. In 1890, New York State held a ceremony to dedicate the official opening of Newark State Custodial Asylum for Feebleminded Women, an institution intended for females in their child-bearing years. Segregation was viewed as the simplest way to prevent people with intellectual disabilities from having children, and even institutions housing both men and women separated them in different buildings. It was not the only way. Laws were passed in some states and localities restricting sexual relations with people defined as feebleminded or epileptic. Involuntary sterilization was practiced in a number of countries up until the 1970s and beyond. The 1927 United States Supreme Court case Buck v. Bell (“Three generations of imbeciles are enough”) is widely cited as illustrating the extremes of what was called the eugenics movement, but eugenic sterilization was widely practiced in countries as diverse as Sweden, Finland, and Japan. Citing eugenics literature from the USA and elsewhere, Nazi Germany murdered hundreds of thousands of people with intellectual and other disabilities as part of its so-called “euthanasia program.”

Not long ago, a book on parents with intellectual disabilities would have been written to arouse popular opinion and stimulate political action against the presumed social menace posed by procreating “defectives.” Today, the hysteria surrounding marriage and procreation of people with intellectual disabilities has waned, although eugenics sentiments persist, if usually unstated. The more common concern is whether people with intellectual disabilities are
fit to be parents. Parents with intellectual disabilities are much more likely than other parents to experience intervention by child welfare agencies on the grounds of suspected abuse and neglect. To be sure, some people with intellectual disabilities are unsuitable to be parents. So are some non-disabled people. More often than not, removal of children from the homes of parents with intellectual disabilities is an unnecessary and drastic measure that could be prevented by offering families the supports, resources, and services they need to be successful.

Although public policy in most countries no longer prevents people with intellectual disabilities from having children, many barriers stand in the way of enabling them to bear and raise children. Parents and guardians can exert subtle and not so subtle pressures on people to be sterilized, willingly or unwillingly. The controlled living situations of many people with intellectual disabilities in residential facilities prevent them from enjoying the freedoms that other people take for granted. People cannot have sexual relationships if they are under the constant supervision and control of others. It does not always take a law or public policy against people with intellectual disabilities having children to prevent them from expressing human sexuality.

The contributors to this edited volume, Parents with Intellectual Disabilities, Past, Present, and Futures, ask different questions than whether people should be permitted to be parents. Their focus is on the experiences and perspectives of people with intellectual disabilities who are parents and on ways to support them in this role. Four features of this volume make it stand out.

First, the contributors to this volume are committed to the human rights of people with intellectual disabilities and their equal participation in society. Their stance is consistent with the 2006 United Nations Convention on the Rights of Persons with Disabilities, which calls upon states to eliminate discrimination against people with disabilities with regard to marriage and parenthood and to provide them with assistance in the performance of child-rearing responsibilities. The idea that marriage and parenthood are fundamental human rights of people with intellectual and other disabilities challenges prejudicial and stigmatizing policies and practices that have been found in many countries.

Second, this volume is international in scope. The contributors come from Australia, Denmark, Iceland, New Zealand, North America, and the United Kingdom. Too often, researchers, policy makers, and professionals ignore the lessons that can be learned from other countries. Readers of this volume will benefit from learning about the perspectives and experiences of parents with intellectual disabilities from a range of countries.

Third, the chapters in this volume are based on rich qualitative case studies of parents with intellectual disabilities and those around them. Qualitative researchers sometimes make a distinction between knowing about people and knowing them. To know about parents with intellectual disabilities is to have information about their ages, incomes, number of children, and similar things. To know parents with intellectual disabilities is to identify with them as fellow
human beings who have hopes, dreams, fears, disappointments, and inner struggles. By getting to know people we can learn about how they view the world and their experiences.

Finally, the contributors to this volume are not only interested in understanding the experiences of parents with intellectual disabilities. They also aim to improve policies and practices regarding this population. Many of the chapters in the volume provide practical strategies on how to support mothers and fathers with intellectual disabilities and their children. The volume is filled with sound advice. It is fitting that the volume concludes with a set of excellent recommendations from the Special Interest Research Group on Parents and Parenting with Intellectual Disabilities of the International Association for the Scientific Study of Intellectual Disability.

The question of whether adults with intellectual disabilities should be permitted to be parents is the wrong question to ask. As a matter of respecting human rights, societies should not attempt to restrict the ability of any adult to become a parent and to raise children merely on the basis of disability. As a practical matter, they have never been able to prevent people with intellectual disabilities from becoming parents. The contributors to this volume ask the right questions about parenthood and intellectual disabilities and provide some sound answers to these questions.

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Acknowledgments

We present this first international volume on parents with intellectual disabilities with enthusiasm and pride. We offer it as a part of the growing scholarship around the world on families headed by people with intellectual disabilities. Many individuals, organizations, and institutions have made this book possible. We are grateful to all of them. Most important, however, are the parents who have participated in our research projects, collaborated with us, and generously shared their lives and experiences with us. This research and collaboration, which has taken place over a period of almost two decades, made it possible to create this book. We also want to thank all those who have contributed chapters to this volume for their willingness to work with us on this exciting project.

While editing this book we have lived in different parts of the world, in Australia, Canada, and Iceland. Meeting to work together has therefore required extensive travel. Our universities have provided the support that has enabled us to do this. The University of Iceland awarded Hanna Björg and Rannveig research semesters and travel grants to travel to Canada and Australia in 2007. The Icelandic Centre for Research (RANNIS) and the University of Iceland Research Fund provided Hanna Björg and Rannveig with research grants for their research with parents with intellectual disabilities. The University of Sydney provided travel grants to supplement support from the International Association for the Scientific Study of Intellectual Disabilities (IASSID) for Gwynnith’s participation in the 2nd European Congress of the International Association for the Scientific Study of Intellectual Disabilities, Maastricht, The Netherlands, and to travel to Iceland, in June 2009.

We also want to acknowledge our colleagues in the Special Interest Research Group (SIRG) on Parents and Parenting with Intellectual Disabilities. This SIRG is part of IASSID, the International Association for the Scientific Study of Intellectual Disabilities, and has been an encouraging and stimulating context for
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Chapter 3 Acknowledgments

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Chapter 7 Acknowledgments

The research projects that provide the basis for this chapter were supported by grants from RANNIS, the Icelandic Centre for Research, and the University of Iceland’s Research Fund. We are grateful for their support of our research. We also want to thank all the parents who have collaborated with us in these research projects.

Chapter 10 Acknowledgment

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Introduction

Gwynnyth Llewellyn, Rannveig Traustadóttir, David McConnell, and Hanna Björg Sigurjónsdóttir

In September 1996, in Snekkersten, a small town north of Copenhagen in Denmark, an historic event took place with the convening of the first international conference on parenting with intellectual disabilities. A small group of distinguished academics from eight different countries gathered to present their research findings about the lives of parents with intellectual disabilities. This conference, convened by the Danish Ministry of Social Affairs and supported by the European Union, initiated a train of events which led to the genesis of this book. The then Danish Minister of Social Affairs, Karen Jespersen, provided the preface to the conference report on *Parenting with Intellectual Disability*. She noted that the issue of parenting by people with intellectual disabilities was taken up by the media on regular occasions, and that there was much debate in Denmark and in other countries about the right to marry and have a family, going on to say “that there is nothing unusual in the fact that some intellectually disabled individuals want to have children, and to many of them this is part of leading a normal life” (Danish Ministry of Social Affairs, 1996, p. 6).

Over a decade and a half later this statement remains true, with an increasing number of people with intellectual disabilities having children and establishing their own families. This is due to deinstitutionalization, the banning of sterilization in many countries, and the embedding of the principles of normalization and anti-discrimination in legislation. This has resulted in most adults with intellectual disabilities living in the community with many of them developing relationships and starting a family. Parenting by people with intellectual disabilities has been acknowledged in the research literature since Mickelson's
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ey early work in 1947. Despite this early start in research, it is only recently and only in some countries that people with intellectual disabilities are becoming accepted as full citizens and able to enjoy the freedom to have a child if they so desire.

Why a Book about Parenting with Intellectual Disabilities?

Parenting by people with intellectual disabilities is a new field of study. At the outset empirical studies were few and far between and provided a pessimistic and medicalized view of parents with intellectual limitations and their children (e.g., Brandon, 1957; Gillberg & Geijer-Karlsson, 1983). It is only since the late 1980s that research with a social and human rights-based approach has begun. Today there is a growing interest in this group of parents, but the research is placed within many different disciplines and is not always easily accessible. In spite of that, this is a topic of increasing interest to professionals in the fields of disability, family support, child protection, and social services, as well as researchers and scholars in disciplines such as disability studies, sociology, psychology, social work, education, and the health sciences.

This book is the first international publication to bring together research findings from several countries and across many disciplines to provide an informative pan-disciplinary compendium on the topic of parents with intellectual disabilities and their children. The ideas behind the book are quite straightforward. In line with the United Nations The Standard Rules on the Equalization of Opportunities for Persons with Disabilities (United Nations, 1993) and the United Nations Convention on the Rights of Persons with Disabilities (United Nations, 2006), the underlying theme of the book is about equal participation for disabled people, in this case parents with intellectual disabilities. The UN Convention affirms the right of persons with disabilities to marry and found a family in Article 23 (para 1). Further, in Article 23 (para 1 and 2) states are bound to “take effective action and appropriate measures to eliminate discrimination against persons with disabilities in all matters relating to marriage, family, parenthood and relationships…” and “render appropriate assistance to persons with disabilities in the performance of their child-rearing responsibilities.”

Universally, becoming a parent and creating a family of one’s own is a highly valued social role. For people with intellectual disabilities who become parents, however, there are many barriers to their equal participation in this role. Many countries now have policy statements and best practice guidelines; for example, in the United Kingdom, the Good Practice Guidance is designed to improve support for parents with intellectual disabilities (Department of Health/Department for Education and Skills, 2007). Despite these efforts,
significant challenges face people with intellectual disabilities who wish to become parents and those who already are parents. As the first international volume on the topic, this book brings together the most up-to-date knowledge about parenting with intellectual disabilities with all the joys and challenges that this entails. Our sincere hope is that this book will provide readers with knowledge and insights that encourage them to support parents with intellectual disabilities and their children in ways which create and sustain happy and successful families.

Until recently, there has been little attention given to the topic of parents with intellectual disabilities in the training and education of social welfare workers and health services professionals, or in continuing education or post-professional graduate programs. Currently there is limited knowledge about parenting by people with intellectual disabilities among health and social service professionals. This book therefore comes at a time when many practitioners internationally are seeking guidance in how to work with parents with intellectual disabilities in ways that recognize family strengths and promote child and family well-being.

Parents with Intellectual Disabilities: Who Are They?

Parents with intellectual disabilities broadly speaking constitute three groups. First, there are people with intellectual disabilities who, although previously institutionalized, now live in the community and have developed relationships and taken up the rewarding but challenging task of parenthood. The second group is made up of parents who were never institutionalized but have received services for people labeled with intellectual disability more or less continuously for most of their lives. The third group consists of women and men with intellectual disabilities who become parents and are part of what Edgerton (2001) refers to as the “hidden majority” – persons with intellectual disabilities who have mild to borderline cognitive limitations. Typically, these individuals have been labeled as being “slow,” having developmental delay, learning difficulties, or intellectual disability while at school. On leaving school, they manage with varying degrees of success to live ordinary lives in the general community with few or no specialized supports. As young adults they desire to be independent and to be treated no differently from their peers. It is only when they make the transition to parenthood, and confront the steep learning curve that parenting presents for everyone, that their cognitive capacity comes into focus and is again questioned. This questioning has led to several discriminatory outcomes well recognized in the research literature, the main focus of which is an extraordinary over-representation of these parents in care and protection proceedings (Booth, Booth, & McConnell, 2005a, 2005b; McConnell, Llewellyn, & Ferronato, 2002; Taylor et al., 1991).
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Parenting in Context

Parents with intellectual disabilities and their children do not exist in isolation. They are a part of families, social networks, neighborhoods, and communities of interest. Parents also have a past. They come from families, in which they grew up and, like all other children, are influenced by their childhood experiences, including their own parents’ approach to their upbringing (Llewellyn, 1997). They also come to being a parent and parenting their own children, like other parents, based on a lifetime of experience in negotiating their place in family and community life. The difference is that for these parents to establish themselves as independent individuals within their society they have to contend with stereotypes about people with intellectual disabilities and with the stigma and social exclusion that typically accompany the label of intellectual disability.

A fundamental theme in this book is that parents with intellectual disabilities and their children continue to carry on with their lives, in their homes and with their extended families, in their neighborhoods and as part of the society and culture in which they live, in spite of stigmatizing attitudes and exclusionary practices. In the literature, however, all too often parents with intellectual disabilities have been studied without due consideration for their present family and social surroundings or those of their earlier life. They are regarded as “standing alone” and held personally and individually responsible for any difficulty that arises, with little attention paid to their familial circumstances and social situations or the broader community and cultural environments of their lives. The stigmatized views about people with intellectual disability, that they are childlike or childish and dependent on others, become sharply focused when adults with intellectual disabilities become parents. Too frequently it is asked how this woman or this man could provide good enough parenting when they themselves require support from others to live as an adult in the community. This view reveals a commonly held stereotype that people with intellectual disabilities are eternal children and unlikely to become adults and therefore are not capable of taking on adult roles like parenting. This incorrect and pessimistic view has led to many barriers for people with intellectual disabilities as parents.

Insider and Outsider Perspectives

The stereotypical understanding about people with intellectual disabilities makes it hard for others to imagine they could be parents. This also assumes that parenting is a task entirely dependent on the abilities of only one individual, ignoring the important contributions to child rearing in our societies that come
from other parents, extended family, community members, public personnel such as teachers, and institutions like preschools and schools. Another stereotypical view of people with intellectual disabilities as passive recipients of care depersonalizes them and negates any understanding of their contribution as active agents in their own lives and the lives of their children and other family members.

For too long, most studies about parents with intellectual disabilities were conducted from an “outsider” perspective. Only occasionally did researchers try to record and describe the essence of parents’ lives from the perspective of the parents themselves. One example of an “insider” view is Taylor’s (1995, 2000) long-term study of the everyday life of a family he calls the Duke family. Gaining insights into social phenomena through understanding the insider perspective is increasingly accepted in the disability field (Bogdan & Taylor, 1976; Gustavsson, 2000; Walmsley & Johnson, 2003). The chapters in this book take account of parents with intellectual disabilities as social beings, as both actors in their families and communities, and as “acted upon” by the services and systems in their society. In many instances, this understanding comes from studies in which parents with intellectual disabilities are the central narrators on their own lives.

### Learning about Parenting

No child comes with an instructional manual to guide the parents in how to successfully raise them. There are many different ways in which all parents learn about child rearing. One way is from being parented oneself and we all learn about parenting to a greater or lesser extent during our own upbringing. Parents with intellectual disabilities, like most other new parents, may also turn to their own parents and other family members for advice and support, especially when their children are young. Parents can attend parenting classes and there are news-stand magazines devoted entirely to parenting topics and the challenges that parents face, with suggested solutions to overcome these. In addition there are increasingly popular television programs on managing children’s behaviors, many of which can be daunting for all parents.

In the research literature much attention has focused on overcoming the perceived inadequacy of parents with intellectual disabilities and the effects of parent education and training programs on their parenting skills (Feldman, 1994; Tymchuk & Andron, 1992; Wade, Llewellyn, & Matthews, 2008). The findings from the studies on parent education and training have unanimously concluded that parents with intellectual disabilities greatly benefit from these programs and that they can learn to take care of their children successfully (Booth & Booth, 1993; Espe-Sherwindt & Kerlin, 1990; Llewellyn, McConnell, Honey, Mayes, & Russo, 2003; McGaw & Sturmey, 1994).
Parents with Intellectual Disabilities

Parenting is an activity in which there is constant change. In effect, all parents “learn on the job” and adapt and change as their child develops and their needs change. In other words, not only does the child grow and develop in the context of the family, but so does the parent. The chapters in this book place particular attention on how parents develop, and how their parenting changes and grows over time.

Gender and Parenting

Parenting involves adults and children, and of course, men and women. Too often in the research literature and in the popular press, the term parents acts as a proxy or shorthand for mothers. By referring to parents when writing about families, authors ignore the gender differences between mothers and fathers. Gender studies, as well as family studies, have demonstrated the different roles of mothers and fathers within families, in particular when it comes to household work and child care, as well as responsibilities outside the home (e.g., Coltrane, 1989; Connell, 2009; DeVault, 1991). Not only does the term “parents” ignore these gender differences, but in focusing mostly on mothers and calling them parents, this hides the fact that the mother is the one most often responsible for the routine care of home and children. Also, in ignoring gender, the father’s role becomes invisible and is not recognized.

Writings about families and disability have the same shortcomings when it comes to gender as the general family literature. This has been demonstrated in disability studies where there is a call for more attention to gender in relation to disability (Kristiansen & Traustadóttir, 2004; Thomas, 1999). Writings about disability, gender, and family life have mostly focused on disabled women’s lives, including attention to mothers with intellectual disabilities (Mayes, Llewellyn, & McConnell, 2006; Traustadóttir & Johnson, 2000; Wates & Jade, 1999). Much less attention has been paid to disabled men, and fathers with intellectual disabilities have been almost entirely overlooked in research, in the literature, and in health and social care practice (for an exception, see Sigurjónsdóttir, 2004). In this book we have attempted to include a gender perspective and explore the lives and experiences of fathers, as well as mothers. However, we do recognize that both in this book, and generally speaking, mothers continue to attract greater attention when child rearing is the topic of interest in societies around the world.

On Terminology

There is no consensus on terminology about disability. Countries use different concepts to refer to the parents who are the focus of this book. Even in
countries where English is the majority language, the terminology is diverse and politically contested (Eayrs, Ellis, & Jones, 1993). In the United Kingdom “learning difficulties” or “learning disabilities” are the preferred terms, while in the United States of America terms such as “developmental disabilities” and “mental retardation” have often been used. Recently, however, leading disability associations in the USA have taken up the term “intellectual disability,” which is the term most commonly used in Australia and New Zealand. Terminology in other languages is equally varied and complicated and often difficult to translate to English. The term “intellectual disability” is most commonly recognized and used by international associations and organizations.

There are also debates and disagreement about ways to talk about disabled people. Those who follow a social understanding of disability usually say “disabled people,” thereby shifting the focus away from the individual to the experiences of oppression by disabling barriers and environments. Those arguing this view point out that “people with disabilities” implies that disability is inherent to the individual, rather than locating its cause in social arrangements (Morris, 1993; Oliver & Barnes, 1998). Others prefer “people with disabilities,” which is also often referred to as “people first” language. This term is favored by most people with intellectual disabilities who argue that they want to be called “people first,” and not to be addressed first by their impairment (Clement, 2003). In doing this they also want to assert their common humanity, which has often been cast into doubt.

This book is based on a social understanding of disability. Despite that, we have chosen to use the term “people with intellectual disabilities.” Intellectual disability is the term most commonly recognized internationally and therefore seemed logical for an international volume. Also, in using the term “parents with intellectual disabilities” we honor the wishes of the parents we have come to know through our many years of advocacy, research, and friendship.

The Organization of the Book

This multi-authored book aims to link theory and research to practice through providing a clear set of principles to inform good practice and an evidence-based approach to supporting parents with intellectual disabilities. Each chapter provides a brief historical overview of the development of ideas and literature pertinent to the chapter’s topic. Building on this, the current state of knowledge is represented by the most up-to-date research evidence drawing on the chapter author’s own work and the work of his or her colleagues. The chapters conclude with principles drawn from the research to inform practice. The book is divided into two parts.

Part I, Family and Community Life, is largely based on the perspectives of parents and focuses on the everyday lives of parents with intellectual disabilities.
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and their children. In this section the attention is on understanding parents as actors in their families and communities, and their interactions with systems and services.

Part I begins with a chapter titled “Becoming a Mother – Becoming a Father” by Rachel Mayes and Hanna Björg Sigurjónsdóttir. Drawing on findings from studies in Australia and Iceland, this chapter describes the experience of becoming a mother or a father for people with intellectual disabilities and how they negotiate these new roles. The authors illuminate the similarities and differences in experience for men and women. They also challenge service providers and policy makers to recognize that fathers and mothers may be poorly supported by services that do not consider their unique and gendered experiences.

Chapter 2, “Looking Back on Their Own Upbringing” by Gwynnyth Llewellyn and David McConnell, is about parents’ own childhood experiences and how, when people become parents, they look to the past to think about the future. Although there has been little research into the childhood experience of parents with intellectual disabilities, a common assumption is that this must be negative. The authors reveal, however, that mothers with intellectual disabilities experience varied upbringing, with at least half the mothers in a community sample experiencing plenty of love, affection, safety, and security. Practitioners need to keep an open mind about parents’ childhood experiences, endeavoring to understand each parent’s perspective on his or her own upbringing.

In Chapter 3, “Family Within a Family,” Hanna Björg Sigurjónsdóttir and Rannveig Traustadóttir argue that, just like in other families, children of parents with intellectual disabilities are raised within their extended families and with the assistance of various professionals and programs in their home communities. The authors warn against the tendency to ignore this larger context and regard parents with intellectual disabilities as isolated individuals who have the sole responsibility of raising their children. To provide an in-depth view of families headed by parents with intellectual disabilities, and the importance of their extended family networks, the authors present stories of three Icelandic families whom they have followed over an extended period.

Chapter 4 offers insights into the lives of children of parents with intellectual disabilities from a study in which the children are the central narrators of their own stories. This chapter, “Children and Their Life Experiences” by Jytte Faureholm, is based on interview research with 23 Danish children of parents with intellectual disabilities beginning in 1994 when they were middle school aged and ending in 2004 when they were young adults. From their perspective, the young people’s greatest disadvantage came from the stigma that they experienced as children due to their mother being labeled with intellectual disability. By young adulthood, however, most were leading successful lives, due in no small part to their own determination and assisted by the educational and vocational opportunities that were finally made available to them as adolescents.
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Chapter 5, by Gwynnyth Llewellyn and Marie Gustavsson, is titled “Understanding Community in the Lives of Parents with Intellectual Disabilities.” The authors argue, from a study with a small group of Australian parents with intellectual disabilities, that the meaning of community participation must take into account that parents with intellectual disabilities are active agents in their own lives in their communities. It is they who capitalize on their physical presence and their belonging to the valued position of parent in society, opening up for themselves opportunities for social inclusion and connectedness.

In Chapter 6, “Citizenship and Community Participation,” Brigit Mirfin-Veitch analyzes data from a New Zealand study to show how important active citizenship, social networks, and community participation prior to becoming a parent are for greater parenting success. The “take home” message from the findings of this study is the critical importance of educators ensuring that learning and development in the area of citizenship and participation occur for young people with intellectual disabilities as they do for their non-disabled peers. The author argues that although young adults with intellectual disabilities may need support to understand their citizens’ rights and how to exercise those rights, it is essential that they approach parenthood well informed and able to advocate for themselves and their families.

Part I concludes with Chapter 7 by Rannveig Traustadottir and Hanna Bjorg Sigurjonsdottir in which they explore the strategies that parents use in their encounters with services and professionals they fear will remove their children. This chapter, titled “Parenting and Resistance: Strategies in Dealing with Services and Professionals,” draws on the authors’ long-term involvement with parents and argues that, instead of interpreting some of the actions of parents as a part of their intellectual impairment, these behaviors may be better understood as resistance against oppressive conditions and services that exercise power and control over the lives of parents and their children.

While Part I explores the lives of parents with intellectual disabilities and their children and mostly from the parents’ standpoint, in Part II we turn to the systems and services that play such a large role in the lives of families headed by parents with intellectual disabilities. The title for Part II – Human Services Enabling and Disabling Parents with Intellectual Disabilities – captures the essence of the chapters in this section. Human services can support parents to parent successfully and their children to lead happy and productive lives. At the same time, human services can be discouragingly disabling and oppressive, and can raise more barriers and present more challenges to parents with intellectual disabilities than the act of parenting itself.

In Part II the contributors explore the various aspects of the human service system that have an impact on parents’ lives. The contributions begin with a chapter on parent education, which is currently the most well-documented area of human service delivery for parenting and parents with intellectual disabilities.
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Chapter 8, “Parent Education Programs for Parents with Intellectual Disabilities” by Maurice Feldman from Canada, offers a practical guide to the implementation of behavioral and self-directed instructional approaches to teaching parenting skills. There is robust evidence that these approaches are the most effective in parent education programs for parents with intellectual disabilities. The chapter begins with a scholarly review of the development of these programs, elucidates the principles and practices that are known to be effective, and then describes in some detail how to implement efficacious parent education programs.

Chapter 9, “Supported Decision Making for Women and Mothers with Intellectual Disabilities” by Sue McGaw and Sue Candy from the United Kingdom, presents an analysis of the many barriers that confront women and mothers with intellectual disabilities when they are making decisions about everyday and important events in their lives. The authors offer detailed ideas about how to support women and mothers with intellectual disabilities to make informed decisions at the critical life stage of deciding to become a mother and about their active participation in the child protection process if the care and protection authorities become involved in their lives and the lives of their children and family.

Chapter 10, “Turning Policy into Practice” by Beth Tarleton, is based on a study of existing services for parents with intellectual disabilities in the United Kingdom. The aim of this research was to identify examples of positive practices in supporting parents. The study found that although there are positive practices, these are rare and parents were more likely to encounter negative assumptions by professionals who had little knowledge and experiences of working with people with intellectual disabilities. The chapter concludes by suggesting the changes needed in order to bridge this gap between forward-looking policy and current practice.

David McConnell and Hanna Björg Sigurjonsdóttir are the authors of Chapter 11, “Caught in the Child Protection Net.” In this chapter they draw on the available research about child protection processes and practices that involve parents with intellectual disabilities to conclude that these are false presumptions so often made about parents with intellectual disabilities, the authors provide ten points vital to promoting natural justice for parents with intellectual disabilities and their children.

Chapter 12, “Turning Rights into Realities in Québec, Canada” by Marjorie Aunos, Laura Pacheco, and Katherine Moxness, presents the story of how a group of committed researcher-practitioners have worked to close the gap between the right for parents with intellectual disabilities to receive appropriate and timely assistance and current service provision in Québec. The authors argue that a multi-agency and many-faceted approach is needed to effectively support parents with intellectual disabilities and their children. The cross-agency initiative described in this chapter involves the development and monitoring of policy and practice standards, the provision of ongoing professional development and networking, continuing to conduct research on topics